

## Analysing culture

Sociological studies of culture have adopted a broad interpretation to include symbolic aspects of human society, such as beliefs, rituals, customs, values and norms, as well as work patterns, leisure activities and material goods. Whereas values are 'abstract ideals', norms encompass socially acceptable rules or guidelines. These guidelines describe a diffuse view of culture as a shared 'way of life' – what we think, how we act, and the material and symbolic objects with which we identify.

To function as a member of a society, it is important to learn its cultural rules and assumptions, including what (or who) is considered 'normal' and acceptable. Culture is a link with the past as well as a guide to the present. It includes the ties that bind as well as what divide human groups. And as cultures demonstrate continuity, so too they exhibit a degree of flux and capacity for creativity.

The definition of culture has shifted from a location in the artistic and intellectual ideas and activities of an elite to incorporate the pursuits of the whole population. T. S. Eliot's evocation of mid-twentieth-century English culture included a multi-class celebration: 'Derby Day, Henley Regatta, Cowes, the twelfth of August, a cup final, the dog races, the pin table, the dart board, Wensleydale cheese, boiled cabbage cut into sections, beetroot in vinegar, nineteenth-century Gothic churches, and the music of Elgar' (Eliot 1968: 104).

Any attempt to produce a similar list at the beginning of the twenty-first century will probably come up with very different things, or perhaps find that the tremendous emphasis on diversity and difference makes compilation of a common list almost impossible. The significance of these changes in the form and content of national cultures feeds into wider debates about the relationship between culture and society, particularly its material base, and the role played by culture (and more specifically the mass media) in social control and social change. In the mid-twentieth century, there were two very different interpretations. Marxists and Critical Theorists argued that modern (mass) culture was orchestrated by the dominant classes to promote passivity in

## 5 Culture, Media and Representation

In previous chapters, we have concentrated on analyses of social oppression that explore those dimensions related to the social division of labour – marginalization, powerlessness and exploitation. These refer to structural and institutional relations that restrict opportunities for material resources and life chances. We now turn to consider cultural domination, or 'cultural imperialism' (Young 1990). This denotes a form of social oppression in which groups experience symbolic devaluation, in the ways that set them apart as 'Other' submerged in negative stereotypes. Most often, culturally oppressed groups such as disabled people also experience material disadvantages and relative powerlessness. By contrast, non-disabled people's greater access to the means of communication and representation effectively ensures the dominance of the world-view and values of able-bodied 'normality'.

This chapter has three main objectives: first, to review key contributions to the analysis of culture and its relationship to society, the economy and politics; second, to outline the representation of disability in mainstream culture, including debates around 'audience effects' of these media; and finally to examine the development of a disability culture, including disability arts, that seeks to offer a positive alternative to negative stereotypes and the hegemony of 'able-bodiedism' while allowing for 'difference' among disabled people.

the subordinate population, while more pluralistic accounts regarded the media as subject to market competition and consumer choice and only one among many competing sources of political influence in a liberal democratic society (Kellner 1989).

By the 1960s and 1970s, studies of culture had divided again, between refurbished neo-Marxist analyses and new structuralist analyses that stressed the importance of language and the 'scientific' decoding of texts and signs (Hall 1997). Our interest lies with neo-Marxist analyses of the cultural domain as an arena of political struggle. A key stimulus was Antonio Gramsci's analysis of 'hegemony', and how the willing consent of subordinate groups might be achieved through the dominant group's direction of the production and consumption of cultural activities (see chapter 2). This approach was developed by Stuart Hall and his colleagues (e.g. Hall and Jefferson 1976; Hall 1980) in their analyses of 'subcultures' (spanning 'race', gender, sexuality and youth), as potential sources for counter-hegemonies or resistance. The emphasis shifted towards multiple, hybrid cultures characterized by fluid and contested boundaries (Kuper 1999: 216), while cultural politics changed 'from a struggle over the relations of representation to a politics of representation itself' (Hall 1988). In the case of disability, studies began to explore how hegemonic views are secured and challenged, including debates over identity and what it means to be a disabled person or part of a disabled culture.

More recently, studies of culture have come under the influence of post-structuralism and post-modernism (Inglis 1993). Following Michel Foucault, the emphasis on power/knowledge has concentrated on cultural production through discourse. In place of ideological domination, Foucault inserts linguistic-discursive practices. Historically, medical discourse has been pre-eminent in redrawing the boundaries between 'able-bodied normality' and the 'disabled other' (Hughes and Paterson 1997). Post-structuralist analyses 'deconstruct' dominant and 'hidden' readings and representations, and attempt to 'give voice' to those who have been marginalized or silenced.

### Cultural representations of disability

Historically, across European cultures, there has been a 'fascination with spectacles of difference' (Mitchell and Snyder 2001: 210), with a concentration on 'defective' or 'abnormal' bodies and minds. The 'otherness' of disabled people has been exploited as a source of 'entertainment' as well as to stir the fears and emotions of the non-disabled population. In ancient Greece and Rome, 'it would almost seem as if no fashionable household was complete without a generous sprinkling of dwarfs, mutes, cretins, eunuchs and hunchbacks, whose principle duty appears to have been to undergo degrading and painful humiliation in order to provide amusement at dinner parties and other festive occasions' (Garland 1995: 46).

The public display of perceived bodily abnormalities continued throughout the Middle Ages. Many royal courts in Europe retained people of short stature as 'court jesters' or kept a complement of 'fools' - including people with cognitive impairments and learning difficulties, as well as others who feigned 'idiotcy' to provide amusement. It was also common practice for people with perceived 'deformities' to be put on display at village fairs, while some peasant parents 'toured the countryside displaying for money recently born infants with birth defects' (Gerber 1996: 43). The public exhibition of the inmates of 'mad-houses' and institutions continued this practice into the seventeenth and eighteenth centuries.

By the nineteenth century, such displays had developed into 'freak shows', which offered a 'formally organized exhibition of people with alleged physical, mental or behavioural difference at circuses, fairs, carnivals or other amusement venues' (Bogdan 1996: 25). These flourished in Europe and North America in the nineteenth and early part of the twentieth century, and were complemented by the so-called 'Ugly Laws' in the USA which placed social restrictions on those whose physical appearance might offend or frighten 'normal' people (Bogdan 1996; Gerber 1996). These prohibited the appearance of individuals who were 'diseased, maimed, mutilated, or in any way deformed so as to be

an unsightly, or disgusting object' (Centre for Independent Living 1982: 249).

Disabled people and their organizations took the lead in challenging this tyranny of 'able-bodied' assumptions in mainstream culture. As Paul Hunt argued, disabled people 'are set apart from the ordinary' as if a direct 'challenge' to commonly held societal values. This attitude characterizes disability in industrial capitalist societies as a 'personal tragedy' in which 'people's shocked reaction to the "obvious deviant" stimulates their own deepest fears and difficulties, their failure to accept themselves as they really are and the other person simply as "other"' (Hunt 1966a: 152).

Others have regarded the cultural meanings associated with 'dread diseases', such as cancer and HIV/AIDS, as so powerful that 'it is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped' (Sontag 1991: 3). Moreover, corporeal descriptors (such as 'cancer', 'insane', 'crippled') are widely employed as shorthand for social, political and economic crises and calamities. And yet, while illness and impairment most often trigger negative reactions, they have also been associated with a partial romanticization. For example, in the nineteenth century, tuberculosis, or 'consumption', became closely linked with individual creativity and artistic sensitivity, as in the case of well-known novelists and poets, including Robert Louis Stevenson, Katherine Mansfield and John Keats (Sontag 1991).

Most typically, then, Western cultures identify and mark out certain people as 'different' or 'Other' – particularly those perceived as having flawed or ugly bodies.

Our disability frightens people. They don't want to think that this is something which could happen to them. So we become separated from our common humanity, treated as fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity. (Morris 1991: 192)

Louis Barrye (1966) offers an early analysis of the literary representation of impairment as impotence in D. H.

Lawrence's *Lady Chatterley's Lover*. Children's stories are replete with their own brand of courage, fear, pity and abhorrence (Shearer 1981). Disability writers note that disabled people are absent in culture, but their primary grievance is that, when present, they are represented in a wholly stereotypical way. The concentration on stereotypes such as Shakespeare's Richard III, Dickens's Tiny Tim and Melville's Captain Ahab have been supplemented by wide-ranging and in-depth studies of the medicalization of disability, with its curative and rehabilitative themes, as well as its enduring association with the 'grotesque' and supernatural (Snyder and Mitchell 2001). 'What we fear, we often stigmatize and shun and sometimes seek to destroy. Popular entertainments depicting disabled characters allude to these fears and prejudices or address them obliquely or fragmentarily, seeking to reassure us about ourselves' (Longmore 1987: 66). Further, 'The most prevalent image in films and especially in television during the past several decades has been the maladjusted disabled person' (p. 70).

Academic studies of impairment and disability representation took off slowly through the late 1980s, particularly in the USA (Biklen and Bogdan 1977; Zola 1985; Gartner and Joe 1987; Klobas 1988). These point overwhelmingly to the negative cultural stereotyping of people with impairments. The 'metaphorical uses of disability are well documented' (Zola 1985: 5). The primary themes of pity and fear are supplemented by diverse images of menace, loathing, innocence and courage. Disabled people are depicted 'in the passive voice' and as 'victims' or 'sufferers'. These images permeate media aimed specifically at children (Quicke 1985; Davidson et al. 1994). Popular cartoon characters, such as Elmer Fudd and Mr Magoo, are set apart because of their physical and intellectual 'defects'.

In one of the most cited collections, *Images of the Disabled*, *Disabling Images* (Gartner and Joe 1987), Laurence Kriegel concludes, after reviewing sources as diverse as *Lady Chatterley's Lover* and *Moby Dick*, that 'The world of the crippled and disabled is strange and dark, and it is held up to judgment by those who live in fear of it. The cripple is the creature who has been deprived of his ability to create a self... He must accept definition from

outside the boundaries of his own existence' (Kriegel 1987: 33).

TV portrayals of impairment and disability are the most widely researched. The absence of disabled people, and their lack of appearance in major roles, are long-established findings in American studies (Zola 1985). People with impairments lead one-dimensional lives, as dependent, unproductive and in need of care. The dramatic focus centres on their interaction with health care or social welfare professionals. As Harlan Hahn (1989) notes, the 'good parts' of ordinary lives – love, romance and sex – are largely absent or not stressed in disabled character's lives. Nor is there much interest in exploring disabling social barriers. Instead, impairment is portrayed as something to be eliminated or overcome (Longmore 1997).

Content analyses of the British media provide a similar picture. For example, Guy Cumberbatch and Ralph Negrine (1992) monitored television output over a six-week period during 1988. Their central findings, reinforced by more recent studies (Ross 1997), are that television programmes consistently adhere to a 'personal tragedy' approach. The most prevalent story-lines link disabled people with medical treatment or cure, together with programmes focusing on their 'special achievements'. Moreover, the representations of disabled people are highly stereotypical, depicting them not as ordinary members of society, but using them to evoke emotions of pity, fear or admiration. Newspaper reporting of disability has attracted similar criticism (Smith and Jordan 1991). A limited number of themes dominate newspaper coverage, mainly health, fund-raising, charity, and personal tragedy stories.

John Berger's *Ways of Seeing* (1972) details the social positioning of bodies through their visual representation. Photography was notoriously at the centre of scientific initiatives to classify physiognomy and impairment, as well as central to the Nazi promotion of the classical 'Aryan' body. However, attempts at more positive images too easily slip into 'denial, disavowal or suppression of the struggle and oppression' (Hevey 1992: 103). This is demonstrated in media coverage of President F. D. Roosevelt whereby only a handful of photographs out of 35,000 showed him as a wheelchair user (p. 102).

A summary audit of media's preference for 'crippling images' includes a fondness for 'wonder cure' stories, the role of charity appeals, the invisibility of disabled people on television, the stereotyped portrayal of disabled characters, and the under-employment of disabled people in TV and radio (Karpf 1988). The most frequently documented cultural stereotypes represent the disabled person as pitiable and pathetic, an object of violence, as sinister and evil, as atmosphere or curio, as 'super-cripple', as an object of ridicule, as their own worst enemy, as burden, as sexually abnormal, as incapable of participating fully in community life, and as 'normal' (Barnes 1992). While the latter suggests a solitary positive viewpoint, it is also the least widely expressed, and its representation of 'normality' largely ignores the social oppression of disabled people.

More recently, this focus on the under- or misrepresentation of disabled people has given way to studies highlighting the mediation of other social factors, such as gender, ethnicity, class and age. Studies of disabled women in literature suggest that they are used primarily as a metaphor for addressing some broader theme. Thus, dramatic interest focuses on their role as tragic or saintly figures, who may perhaps be 'saved' by an 'able-bodied' man:

In all these instances, disability sets the tone for the women's interaction with others. Her competence at homemaking chores, her educational attainments, or her personality have little effect upon the attitudes of others toward her. As other characters react to her disability they are not concerned about her competence, but something much deeper and harder to define. Disability seems to undermine the very roots of her womanhood. (Kent 1987: 63).

Fine and Asch (1988) argue that disabled women are alternatively portrayed as sexually promiscuous or asexual/innocents, denied opportunities to express their sexuality in everyday ways such as clothes, hair style or intimate sexual activity. The reluctance to depict disabled women as sexual beings, or in traditional female roles as wives and mothers, is explored by Helen Meekosha and Leanne Dowse (1997). They illustrate the contradiction between the support by the disabled people's movement for images of disabled people in

'normal' roles and the desire of feminists to challenge gender stereotypes. Equally, the polarization of 'normal' masculinity and disabled impotency accentuates the image of disability as a personal tragedy.

This has led to a growing interest in the cultural representation of the 'normal' body or what Leonard Davis terms the 'hegemony of normality': 'One can find in almost any novel... a kind of surveying of the terrain of the body, an attention to difference – physical, mental and national' (Davis 1995: 41). These themes are pursued in Rosemarie Garland Thomson's (1997) analysis of disability representation in American culture, which spans the traditional freak show, sentimental novels such as *Uncle Tom's Cabin*, and contemporary African-American fiction. She claims that the 'cultural intolerance of anomaly is one of the most pervasive themes in Western thought' (Thomson 1997: 33). Her study draws heavily on contemporary literary, feminist and social theory, particularly post-modernism, to examine how 'corporeal deviance' is a 'product of cultural rules' about 'abled-bodiedness': 'Constructed as the embodiment of corporeal insufficiency and deviance, the physically disabled body becomes a repository for social anxieties about such troubling concerns as vulnerability, control and identity' (Thomson 1997: 6). Most importantly, Thomson also explores an emerging counter-representation: for example, in the novels of Toni Morrison, 'physically disabled or anomalous black women triumph', and the novels 'repudiate stigmatization itself' (Thomson 1997).

Stereotypical and distorted representations of people with physical impairments have been standard fare in cinema film. In the most comprehensive history of such disability representation, Martin Norden concludes that 'the history of physical disability images in the movies has mostly been a history of distortion in the name of maintaining an ableist society' (Norden 1994: 314).

As a visual medium, cinema uses pictures to reveal character, so the physical and emotional 'cripple' was a regular amalgam. The cinema also inherited the entrepreneurial traditions of the freak show, or, as Cecil B. De Mille remarked: 'affliction is much more saleable' (quoted in Norden 1994: 71). While a range of negative stereotypes has predominated,

there have been some positive changes in this imagery. Norden identifies an early exploitative phase (1890s–1930s), when highly stylized images of 'comic stick-figures, freakish beasts, or pitiable objects' (p. 314) predominated. This was followed by a more exploratory phase (1930s–1970s) in which individuals struggled to overcome their personal tragedy. Moreover, up to the 1930s, clear gender stereotypes prevailed – typically 'Sweet Innocent' females, as opposed to male 'Comic Misadventurers', 'Tragic Victims', 'Noble Warriors' and 'Obsessive Avengers' (Norden 1994: 315). He distinguishes a third phase (1970s–1990s) when impairment was dealt with in a more 'incidental' way across very different contexts: rehabilitation, struggles for social justice, and personal relationships, including sexuality. Nevertheless, outright condemnation of film movies for disseminating 'nightmarish images of disability as a threat to social stability' (Snyder and Mitchell 2001: 369) must be set against individual exceptions such as the easy integration of a Deaf character in *Four Weddings and a Funeral*.

Paul Darke explores similar themes in his textual analysis of disability in films such as *The Elephant Man* (Darke 1994) and *When Billy Broke his Head and Other Tales of Wonder* (Darke 1995). He categorizes the latter as a *rite de passage* movie, in which Billy Golfus, newly impaired after a motorcycle accident, explores the meaning of disabled masculinity in American society. Darke (1998) further explores what he terms 'normality drama'. This is a genre that uses abnormal/impaired characters to represent a perceived threat to dominant views, thus indirectly rationalizing their social marginalization.

One of the most widely cited attempts to locate an aesthetic and theoretical analysis of bodily representation within a broader concern with social and political context is advanced by David Hevey in his study of charity advertising, *The Creatures Time Forgot* (1992). He examines how British charities 'market' particular impairments in ways parallel to the 'branding' of commercial products in their search for public support. A hallmark of the early charity approach is the stark image of the person with an impairment, usually in black and white, which centres on their physical 'flaw'. Its purpose is to evoke fear and sympathy in the viewer. 'Charity

advertising sells fear, while commercial advertising sells desire' (Hevey 1992: 35). It sets up a 'dependent impairment, active charity dynamic' (pp. 35-6), and is no less than the 'visual flagship for the myth of the tragedy of impairment' (pp. 51-2) and a means of victim blaming. Charity representations accentuate pity for people with impairments and their general dependence and helplessness.

The aim is to stimulate an emotional reaction from the viewer that turns the subject into an object of desire/fear. This has particularly threatening consequences for many disabled women.

There are also dangers here of the advertising industry moving from selling the beautiful and sculptured non-disabled body to selling the beautiful and sculptured disabled body. For women with degenerative or acquired disabilities, or illnesses not amenable to physical body sculpting, these images can further demoralize and undermine their sense of self-worth. (Meekosha and Dowse 1997: 97-8)

Nevertheless, some charities have attempted to move away from their reliance on disabling imagery. This approach has been categorized as, 'look at the ability not the disability'. Recent initiatives in Britain by SCOPE (formerly known as the Spastics Society) focused on prejudice and discrimination without dispensing entirely with a personal tragedy approach. The Leonard Cheshire Foundation followed suit in its 'Enabled' advertising campaign. Mencap, a charity for people with learning difficulties, replaced its tearful 'Little Stephen' logo with a more positive representation that embraced citizenship and social rights (Corbett and Ralph 1994: 11).

Overall, through the last quarter of the twentieth century, there has been a discernible rise in more 'positive' cultural and media images of disabled people. Since the 1980s, disabled characters have begun to appear in high-profile advertisements for Kodak films, Levi jeans and McDonalds (Longmore 1987). There are also more 'disabled' characters, although not all are played by actors with impairments, and disability story-lines are underplayed in British and American soaps and dramas (Pointon 1997).

## Audiences and media effects

In analysing the media, attention is focused on the processes of encoding and decoding. Analysis of the production of these texts – their encoding – examines the social context and constraints in producing TV news items, newspaper stories and information on the internet. Why are specific stories selected as 'newsworthy' – including why some impairment groups rarely appear? How are these related to the technical constraints and demands on presenting items within different media?

The next, crucial question is about the decoding process: how do audiences receive and understand media information and messages? The literature divides between an answer which presumes both intent and desired impact, perhaps linked with a hidden agenda serving dominant interests, and another that suggests a more variable impact. This reinforces a further divide, between studies that posit a 'top-down' manipulation and those that allow for an uncertain audience response.

As the media have grown in importance through the twentieth century as mechanisms for communicating ideas and information, so their significance as a terrain of cultural politics has increased. There has been a widespread presumption, in both the American and the British literature on disability, that cultural and media imagery has a potent, if not direct, effect on its audience. This remains an empirical question, but it sits uneasily with recent characterizations of late twentieth-century culture that stress the significance of social and cultural diversity rather than homogeneity. This raises doubts about the capacity of the media to disseminate specific messages.

Hiberto, a straightforward 'hypodermic syringe' model has prevailed, in which the 'naturalness' of disability is promoted/reinforced across the range of cultural forms. Against this, a 'uses and gratifications' approach claimed that people are not simply inert or passive, but actively interpret media materials in accordance with their own needs and interests (McQuail 1972). Hence, assumptions that the media are always able to 'manufacture consent' to the dominant order

are set aside, by acknowledging that the media may be 'read' in contrary ways, so that audiences sometimes revise or reject intended messages (Hall 1980, 1997).

Models tend to be static and do not necessarily reflect contradictory representations and change over time. They help us 'fit' media stories into boxes, but do not necessarily aid in a more complex analysis of the processes involved in disability construction. Thus overall, the variety of elements of media analysis necessary to understand disability cannot be reduced to a simple categorization of content, but require a complex sensitivity to multiple dimensions of the process. (Meekosha and Dowse 1997: 95)

The possibility of an active audience remains under-explored in studies of the media and disability. Certainly, media audiences will have already established views regarding disability. Nevertheless, the media's pivotal role in the dissemination of information, images and opinions has been identified in HIV/AIDS (Kitzinger 1993) and in mental illness (Philo 1996). Hence the widespread assumption that the media's negative stereotypes of disabled people reinforce existing patterns of discrimination, and in some instances, as with highly stigmatized groups such as those with 'mental illness', may contribute to a 'moral panic' about their inclination to commit random acts of personal violence.

If it is accepted that audiences may interpret media information and representations in many different ways, it must also be allowed that different audience 'readings' may in part be attributed to confusion over whether the 'author' or those involved more generally in cultural production always have a 'message' that they are trying to get across. What 'reading' should one place on H. G. Wells's short story 'The Country of the Blind' published in 1904, which tells of a man called Nunez who falls off a mountain into an isolated valley populated entirely by people with congenital blindness. He presumes wrongly, as it turns out, that 'in the Country of the Blind, the One-eyed Man is King' (Wells 1979: 129). Issues of 'able-bodied' superiority and the civilizing mission of the non-disabled person abound, but in the end, the blind population reject Nunez (who represents 'civilization') in favour of the 'obvious' merits of their own way of life. Again, film

representations often generate polarized interpretations among both academic and lay audiences (Shakespeare 1999). Is Tod Browning's 1932 classic horror film *Freaks* a breakthrough in disability representation or a 'misplaced' attempt to 'humanise the freaks'? (Snyder and Mitchell 2001: 380).

### Disability culture

Is there a distinctive disabled people's culture? Lois Bragg (cited in Peters 2000: 584) answers 'no' on the grounds that disabled people's claim fails to meet the qualifying conditions of a common language, a historical lineage, cohesion, political solidarity, acculturation from an early age, generational/genetic links, and pride in difference. She is not the first to identify Deaf Culture as the sole exception: 'The Deaf community apart, there is no unifying culture, language or set of experiences; people with disabilities are not homogeneous, nor is there much prospect for trans-disability solidarity' (Bickenbach 1999: 106). In complete contrast, Simi Linton argues that disabled people in America have 'solidified' as a group.

We are everywhere these days, wheeling and loping down the street, tapping our canes, sucking on our breathing tubes, following our guide dogs, puffing and sipping on the mouth sticks that propel our motorised chairs. We may drool, hear voices, speak in staccato syllables, wear catheters to collect our urine, or live with a compromised immune system. We are all bound together, not by this list of our collective symptoms but by the social and political circumstances that have forged us as a group. (Linton 1998: 4)

Susan Peters similarly argues that disability culture is alive and vibrant. It is held together by shared values of 'radical democracy and self-empowerment' as well as 'identity, voice, justice and equality' (Peters 2000: 593). And, contra the doubters, disability culture demonstrates commonalities in historical/linguistic terms, by a commitment to social/political issues and changes, and through its personal/aesthetic values. Concerns that the emphasis on 'difference' will thwart

a coherent and unifying culture are rejected on the grounds that difference is a source of strength and allows people to generate new forms of solidarity (Peters 2000).

Disability culture presumes a sense of common identity and interests that unite disabled people and separate them from their non-disabled counterparts. The exact bases for group cohesion and consciousness will vary, as will the level and form of any engagement in cultural activities. This division between 'insiders' and 'outsiders' is developed and maintained by specific cultural styles, customs and social interaction, such as in segregated, residential schooling, or by a distinctive set of experiences. There is a further presumption that a disability culture rejects the notion of impairment difference as a symbol of shame, and stresses instead solidarity and a positive identification. At the same time, a general disability culture may be contrasted with subcultures located around specific impairment groups. Furthermore, because most disabled people acquired their impairment in later life, their embrace of disability culture is inhibited by their previous immersion in a non-disabled environment.

Whatever one's conclusion regarding this debate, further questions remain about the value or possibility of a separate cultural identity:

Firstly, there is a great deal of uncertainty amongst disabled people whether we do want 'our own culture'. After all, we all have had the experiences of resisting being treated as different, as inferior to the rest of society. So why now, when there is much greater awareness of our desire to be fully integrated into society do we suddenly want to go off at a tangent and start trying to promote our differences, our separate identity? Secondly, at this time, even if we do want to promote our own identity, our own culture, there has been precious little opportunity for us to develop a cultural life. (Finkelstein, quoted in Campbell and Oliver 1996: 111)

Historically, embryonic disability communities take form among those segregated together on the basis of their impairments. With the growth of industrialization and urbanism, the resort to specialized institutions for the most severely impaired or 'threatening' individuals expanded significantly across North America and Britain (Parker 1988). For the

disabled inmates, the shared experiences in such areas as schooling and rehabilitation agencies raised the potential for developing a shared, albeit 'defensive', consciousness that sowed the seeds of a more critical and proactive disability culture (Hunt 1966a).

From the 1960s, amidst gathering forms of social protest, residential institutions provided a fertile seed-bed for developing a collective identity. The emergence of the Independent Living Movement in the USA was further stimulated by the mobilization of disabled veterans from the Vietnam War. In Britain, disabled people's campaigns can be traced back to action by a group of disabled residents at the *Le Court* Cheshire Home in Hampshire. These early years were taken up with identifying common interests and grievances and alternative ways forward (Campbell and Oliver 1996).

The crucial move in developing a disability consciousness has been the critique of disability as an individual problem that requires individual (mainly medical) solutions. One of the key mechanisms through which personal consciousness may be transformed into a collective awareness is by sharing experiences with other people in similar situations through small group meetings, books, poetry and the like (Campbell 1981; Campbell and Oliver 1996). Since the 1970s, there has been a steady growth in disabled people's writings, including the appearance of an 'alternative' disability press, such as *Disability Rag*, the unofficial newspaper of the American Independent Living Movement, which began publication in 1980, and *Mouth* (Davis 1995; Brown 1997). Such initiatives sensitized a growing number of disabled people to the commonalities of disability.

Disabled people have also emulated other oppressed groups in appropriating disabled imagery, with claims of building or celebrating a 'crip culture'. Just as humour is widely used to demean disabled people, so too it is employed by disabled people to generate 'insider' recognition and solidarity, by identifying common enemies and interests, and providing a bond of 'crip humour' to disabled people's culture (Shakespeare 1994).

Increased political activism led to new representations of disabled people as active participants in protests against inaccessible buildings and transport, and welfare benefit cuts;

charity events such as Telethons as well as a broad range of campaigns for civil rights. These included disabled people chaining themselves to buses and trains, blocking roads, and crawling along the streets (Pointon 1999). In Britain, the Direct Action Network (DAN) has been in the vanguard of militant, high-profile protest actions outside Government offices, on the streets, on public transport, 'sticking two fingers up at the traditional charity-campaign image of disabled people as quietly respectable, submissive types' (Daniel 1998: 22).

This contrasted starkly with news media portrayals of disabled people as embroiled within a personal tragedy, and courageously struggling against the odds. Initially, newspapers and TV were bemused and uncertain about what to do. References to the 'last civil rights battle' were mixed with concerns that disability protest threatened to alienate supporters, or that acceding to the protesters' demands for an accessible environment was simply too expensive to contemplate. The broadsheet the *Sunday Telegraph* included a condemnation of 'the furious Quasimodos' who had engaged in a 'red paint' demonstration in Downing Street (Wilson 1997).

### Deaf culture

The process of exclusion has been fundamental to the development of Deaf culture. It has its roots in the eighteenth century and the changing perception of 'Deafness' (Davis 1995). Until that time, Deaf people were excluded from the aural culture, isolated from each other, and lacked a shared, complex means of communication.

Growing urbanization encouraged Deaf people to congregate in specific areas. Everyday social interaction with other Deaf people stimulated the growth of sign language as a means of communication. This is illustrated in the growth of a Deaf community in Paris in the second half of the eighteenth century (Lane 1989), and in North America, revealed in Nora Groce's study *Everyone Here Speaks Sign Language: Hereditary Deafness in Martha's Vineyard* (1985). In this island off Cape Cod, Massachusetts, a relatively high proportion of the island's population in the nineteenth century

were Deaf, sign language users; but, most significantly, signing was learned by a significant proportion of the rest of population. Groce quotes the comments of a *Boston Sunday Herald* reporter in 1895: 'The kindly and well-informed people whom I saw, strange to say, seem to be proud of the affliction – to regard it as a kind of plume in the hat of the stock. Elsewhere the afflicted are screened as much as possible from public notoriety' (Groce 1985: 51). The assumption is that the Deaf minority was relatively well integrated into the 'normal' life of the community. More often, Deaf people have been insulated from exclusion by non-disabled culture by relying on a 'camaraderie' with like others in ways that have been 'historically created and actively transmitted across generations' (Padden and Humphries 1988: 2).

However, in seeking to understand the cultural experience of Deafness, it is necessary to distinguish between people with a hearing impairment – who may be described as deaf, or hard of hearing – who have often acquired or developed hearing loss, and are not native users of British Sign Language (BSL), and people with congenital hearing impairment who have been immersed in a BSL environment (whether at home with Deaf parents or by attending a Deaf school), and who define themselves as Deaf. It is the latter group that constitutes the members of a Deaf culture that is located in a distinctive, shared language. In addition, the community may also comprise certain hearing people, such as the children of Deaf adults who have grown up with sign language and other aspects of Deaf culture (Davis 1995).

Many Deaf people explicitly refer to themselves as a linguistic and cultural minority, making the analogy with minority ethnic groups, who are similarly likely to be excluded because they lack fluency in the dominant language. This goes with a resistance to being identified as disabled people or people with impairments (Lane 1995). It is also manifested in opposition to medical solutions, such as cochlea implants, that may restore some hearing function, and genetic screening to identify for termination of a foetus with a likely hearing impairment.

In their struggles to avoid assimilation within an 'oralist' culture and to retain their separate cultural identity, the Deaf community supports special Deaf schools as bastions of Deaf

culture generally, and more specifically for their emphasis on teaching and learning through the medium of British Sign Language (BSL):

Basically D/deaf people whose first language is BSL should be seen as a linguistic minority... our schools go back to the 1790s and our clubs to the 1820s. Our language is much older. D/deaf people marry each other 90% of the time, 10% have D/deaf children. Our customs and traditions have been passed down the ages and these, together with our values and beliefs, constitute our culture... the whole definition of culture is so much wider than the one the disability movement is espousing. (Ladd, quoted in Campbell and Oliver 1996: 120)

While there are those with a hearing impairment who do not identify in the same way with Deaf culture, it is only a minority who see themselves as part of the broader disabled population and disability culture (Corker 1998a). This reflects the uneasy 'stand-off' between Deaf people and organizations of disabled people that has often inhibited joint political action.

### *Disability arts*

Disability culture is built on the premiss that there is a moral and political obligation to celebrate difference. The emergence of a disability arts movement marks a significant stage in the transition to a positive portrayal of disabled people, and a sure sign of its political awakening: 'disability arts would not have been possible without disability politics coming along first. It's what makes a disability artist different from an artist with a disability' (Sutherland 1997: 159).

The disability arts movement encompasses several, reinforcing dimensions. First, it argues for disabled people to have access to the mainstream of artistic consumption and production. Second, it explores the experience of living with an impairment. Third, and most crucially, disability arts offer a critical response to the experience of social exclusion and marginalization. It entails using culture and the media to

expose the discrimination and prejudice that disabled people face, and to generate a positive group consciousness and identity (Barnes et al. 1999). Nonetheless, there remains a crucial distinction between 'disabled people doing art' and 'disability arts', which is more overtly 'political'.

Disability arts are potentially educative, expressive and transformative. They emphasize the potential of cultural action as a progressive, emancipatory force at both individual and social levels. The focus on oppression and injustice provides the rationale for a diverse array of cultural interventions in which subversive representations or performances illuminate and confront discriminatory barriers and attitudes. Where the audience is primarily non-disabled people, some disabled artists adopt a deliberate tactic of 'outing' impairment, often their own, in an attempt to counter social conventions that impairment is something best kept hidden. For some the shock value of a public display of impairment is a first stage in making a non-disabled audience feel guilty for experiencing revulsion. At the same time, there is an uncertain boundary line between challenging disability and encouraging voyeurism or pathologizing impairment.

By contrast, traditional paternalistic approaches believe that disabled people are incapable of communicating their thoughts and feelings through the arts, except perhaps as a means of individual therapy or part of a process of rehabilitation. This view has pervaded the activities promoted within special schools, day centres and segregated institutions. These tend to depoliticize creativity, although they are instead exploited for commercial purposes, such as charity Christmas cards. While there is a place for art therapy, disabled people have increasingly developed a more reflective and active orientation: 'Introducing disabled people to the social role of artistic creativity and opening a debate about disability culture is a dynamic way of assisting disabled people to challenge their assumed dependency and place in mainstream society' (Morrison and Finkelstein 1993: 127).

In North America, the emergence of a disability consciousness may be traced through the 1960s and 1970s (Bowe 1978). Autobiographical accounts flourished, and while most reflected a standard 'living with my impairment' approach, there were notable exceptions, such as Irving Zola's (1982)

story of his personal and intellectual journey in rethinking disability and identity. This American and Canadian literature was extended with an increasing production of novels, comedy, songs, poetry, drama, paintings and sculpture. These conveyed an emerging sense of group identity and interests (Saxton and Howe 1988; Davis 1995; Hirsch 1995; Tremain 1996). These contributions flowered as a complement to disability rights protests, so that by the early 1990s a distinctive 'Disability Culture Movement' had been identified (Shapiro 1993; Longmore 1995; Brown 1997).

Parallel trends in Britain include the first production of a television programme in 1975 specifically for (and increasingly produced by) disabled people, entitled *Link*, and the production of a range of newsletters and magazines by disabled people and groups. This has included a remarkable growth in contributions from disabled poets, musicians, artists and entertainers (Morrison and Finkelstein 1993). *In From the Cold*, the magazine produced by Britain's Liberation Network of Disabled People, appeared between 1981 and 1987. *Coalition*, the magazine of the Greater Manchester Coalition of Disabled People (GMCDP), was first published in 1986 and is still going strong; while *DAIL* (Disability Arts in London) Magazine has been running since 1987. The number of conferences, exhibitions, workshops, cabarets and performances has also continued apace (Poynton and Davies 1997). By the late 1980s, a number of 'specialist' disability programmes were being transmitted on British television, and in 1993 the British Broadcasting Corporation set up the Disability Programmes Unit, staffed mainly by disabled people, that promoted a critical awareness of disability issues.

There has been increased recognition of the importance of involving disabled people in mainstream culture. In the USA, The Americans with Disabilities Act (ADA), for example, forced suppliers of television sets to build in a decoder chip so that D/deaf people could receive the 'closed caption' (a type of subtitling) system for viewers with hearing impairments. In the UK, National Lottery funding was awarded to the Royal School for the Deaf to help build Europe's sign language video library – the first phase of a £1 million National Sign Language Video Centre.

The disability arts movement is important in that it provides space for a critical reflection on ways to empowerment (Morrison and Finkelstein 1993). Nevertheless, there are uncertainties about its reflection of difference, and whether disability art and culture will be assimilated into mainstream culture and neutralized.

## Review

Analyses of cultural domination or 'imperialism' have highlighted the dominance of disabling images across the range of modern media. Historically, disabling imagery has reinforced the social exclusion and oppression of disabled people. Until recently, it has been specific impairment groups rather than disabled people generally, who have forged a common identity. The disabled population is scattered, isolated and divided, rather than a cohesive, self-conscious 'community'. There have been too few organizations controlled by disabled people promoting their own interests. The multiple experiences and identities among disabled people also inhibit collective mobilization and identification. However, a disability culture is emerging. Disabled people are becoming politicized and aware of their collective interests. This sets the scene for a struggle by disabled people to supplant oppressive media and cultural representations with others that reflect their own experiences and values. It heralds the generation of a disability culture that expresses and sustains a positive disabled identity.

A similar struggle has been under way with respect to disabled people's exclusion from political institutions and processes. In chapter 6, we discuss how political domination is exercised, and how disabled people are fighting back and attempting to redefine disability politics.